Macular Society
Beating Macular Disease

Emotional impact of sight loss

Helping you understand the emotions you might be feeling due to sight loss.

This leaflet is available on audio CD.

You don't have to face macular disease alone. For the best information and support call us on 0300 3030 111.

Age-related macular degeneration (AMD) is the most common form of macular disease.

Many areas of life are affected by macular disease, such as reading, writing, watching TV, driving, recognising faces and communicating visually. This can have a huge impact on the way people think and feel about themselves and can be difficult to accept.

Common emotional reactions

Fear

It is very common for people to fear sight loss. A study found that some patients equate the impact of loss of vision with suffering a stroke or having an advanced form of cancer, so it's vital to get the support you need as soon as possible. Please call our Advice and Information Service on 0300 3030 111.

Grief

Many people with macular disease describe the impact of losing their sight as like bereavement. They 'mourn' the loss of their

sight and experience many of the same stages of grief: denial, anger, bargaining, depression and eventually some acceptance.

Isolation

One of the first experiences many people have is a feeling of isolation. This can develop over weeks, months and sometimes even years. People feel anxious and withdrawn and this can cause them to step away from social situations. If you feel isolated, please read our Befriending Service and Macular Society Support Groups information on page 7.

Depression

It is very common for people who have macular disease to experience symptoms of depression, particularly when first diagnosed or if there is a significant deterioration in vision. In fact, people with macular disease are seven times more likely to feel distressed or depressed than people with no sight loss.

Other emotions

Shock, anger, disbelief and denial are all common emotions. In extreme cases people can even experience suicidal thoughts. If you are

experiencing any of these emotions or would like information about our Counselling Service please call our Advice and Information Service on 0300 3030 111.

People tell us...

"I don't want to be a burden to my family and friends"

Family members who are more used to giving help and advice, can suddenly find themselves needing support. They sometimes struggle to come to terms with this.

"People will think I'm stupid"

Poor vision can affect even simple tasks. People can become more accident-prone and may worry about how this is seen by others. People with sight loss are more likely to fall. Fear of falling might stop you doing the things you love or getting out of the house.

"I feel a fraud"

While macular disease can cause serious sight loss, it may not be obvious to anyone else. This can lead to reluctance to appear in public places. Some people don't want to go out at all.

"I don't know how to tell my family"

Many people with macular disease say that one of the most difficult situations to deal with is telling others about their sight condition. They are scared about how their family and friends, neighbours, colleagues and other people will react.

It is extremely common for people to feel apprehensive about 'going public' with their diagnosis. Call our Advice and Information Service for advice about how to explain your sight loss to other people.

Family and friends

The family and friends of a person with macular disease can also be affected by significant changes in emotions.

Supporting someone with a macular condition can be a long-term commitment. It can be frustrating and overwhelming. These feelings are normal and with the right support, family and friends can learn to cope very well.

See our 'Supporting someone with a macular condition' leaflet for more information.

Practical help

Registering as either 'partially sight impaired' or 'severely sight impaired' often makes it easier to get practical help and claim benefits, which in turn may help you overcome some emotional barriers.

For more information please refer to our 'Registering as sight impaired' leaflet.

How we help

Many people appreciate being able to talk about their feelings in a safe and confidential way to someone outside their family or circle of friends.

You might find it helpful to talk in confidence to a professional counsellor.

Our free **Counselling Service** is available to anyone affected by a macular condition at any time during their sight loss journey. It is also available to family, friends, carers or anyone supporting someone with a macular condition.

Sessions are held over the phone enabling us to offer a UK-wide service. We will provide up to six sessions, usually on a weekly basis, although extra

sessions can be provided if needed.

Sessions can be arranged around eye appointments.

All of our counsellors are fully qualified and members of the British Association for Counselling and Psychotherapy (BACP).

To be referred, call our Advice and Information Service on **0300 3030 111**. They will pass your details on to the service co-ordinator and one of our team will contact you within 2 weeks for an assessment.

Our **Befriending Service** can find you a dedicated befriender who will call regularly for a friendly, social chat about anything you like including, but not only, macular disease.

Our network of over 400 **Macular Society Support Groups** stretches across the UK. Each one offers practical and emotional support for people with macular disease, from those living with it today.

Find your local group at **macularsociety.org/groups**

Working with you to Beat Macular Disease:

- We provide the best advice and information on living with macular disease.
- Macular Society Support Groups can help you to beat the isolation of macular disease, by connecting you with other local people who know what you're going through – offering support and companionship.
- Our research programme is focused on finding new treatments and a cure to Beat Macular Disease forever.

Macular Society

PO Box 1870, Andover SP10 9AD

01264 350 551
macularsociety.org
info@macularsociety.org

@MacularSociety

/macularsociety

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